

# Health Reform and Genetic Services Financing

**Kay Johnson**

Johnson Group Consulting, Inc.

Lecturer, George Washington University

Research Associate Professor, Dartmouth Medical School

Presentation to Secretary's Advisory Committee on Heritable  
Disorders in Newborns in Children

January 11, 2011

# The Affordable Care Act (ACA) builds on today's system & policies

- **Genetic Information Nondiscrimination Act (GINA)**
- **Medicaid and CHIP coverage for children**
- **Medical necessity standard in Medicaid's Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program**
- **Federal law that prohibits Medicaid and CHIP from denying children coverage based on their health status**
- **State Newborn Screening and Genetics Programs**
- **Regional genetics and newborn screening collaboratives**
- **Genetic Services Branch HRSA/MCHB/DSCSHN**



# Examples for Context

- Birth defects affect 1 in 33 babies – 120,000 infants per year.
- Developmental disabilities – such as neurological conditions like autism, cerebral palsy and learning disabilities – affect 17% of all US children.
- 14% of children have special health care needs.
- For example:
  - 1 baby in 25,000 in US is born with PKU.
  - 1.2 – 4.0 per 1000 children have hearing loss.
  - 1 in 303 children have cerebral palsy (3 per 1,000).
  - Spina bifida occurs among 2 per 10,000 live births.
  - Sickle cell disease affects an estimated 100,000 Americans.
- Approximately 50 million people of all ages in the US have a disability as a result of an injury or health condition.



Sources: [www.cdc.gov/ncbddd](http://www.cdc.gov/ncbddd); [www.mchb.hrsa.gov](http://www.mchb.hrsa.gov); [http:// genes-r-us.uthscsa.edu](http://genes-r-us.uthscsa.edu); [www.marchofdimes.com](http://www.marchofdimes.com); [www.cshcndata.org](http://www.cshcndata.org);

# Advocate with better leverage

- **Stop slicing and dicing children**
  - Physical versus developmental
  - Illness versus disability
  - Detected through newborn screening versus other detection
- **Develop unified front**
  - Agencies and organizations
  - Families and their advocates
  - Public health versus clinical medicine
- **Take positions on benefits for children with special health needs – applying broadest definition**



# ***Health Care Reform Legislation Taxonomy***

## **National Health Reform Law and Policy Project**

Thanks to Sara Rosenbaum and colleagues  
The George Washington University  
School of Public Health and Health Services  
Department of Health Policy

**<http://www.gwumc.edu/sphhs/departments/healthpolicy/healthReform/>**

## Health Reform Legislation Taxonomy



What does ACA mean in terms of genetics?

# Accessibility & Affordability

- Affordable coverage for more individuals
  - Provides sliding scale tax credits and subsidies on out-of-pocket costs for those with income up to 400% FPL. (2014)
  - Combination of requirement to have coverage and increased access to affordable coverage. (2014)
- Now:
  - Allows young adults to stay on their parents' health care plan until age 26.
  - Eliminates **lifetime limits** and prohibits health plans from dropping those who get sick.
  - Assures access to affordable insurance for uninsured with pre-existing conditions through a temporary subsidized **high-risk pool**.



# Pre-existing Condition Exclusions

*“No child should be denied coverage for a pre-existing condition. The pre-reform health system allowed insurance companies to deny coverage for children with pre-existing conditions like asthma, diabetes and birth defects. Families were torn between finding affordable insurance for their sick children and a lack of security about what new employment would mean for their health coverage. ....*

*The [ACA] statutory provision will be improved through regulation, and many children who are currently denied health care coverage because of pre-existing conditions will be able to access the affordable health insurance they so desperately need and deserve.”*



Judith Palfrey, President AAP, March 29, 2010



# Patient's Bill of Rights

- The Departments of Health and Human Services, Labor, and Treasury issued regulations to for a new Patient's Bill of Rights under the ACA.
- Effective 9/23/2010 the following protections began:
  - Prohibit denial of coverage to children because of a pre-existing condition.
  - Ban on lifetime dollar limits on benefits.
  - Restriction on the annual dollar limits on coverage.
  - Coverage of recommended preventive services with no deductible, copayments, or coinsurance.
  - Access to dependent coverage for adult children under the age of 26 if they don't already have access to their own job-based coverage;
  - Choice of any available primary care doctor or pediatrician in a plan's network and direct access to an OB/GYN without a referral.
  - Access to out-of-network emergency care without prior authorization or higher cost sharing than would otherwise be charged.
  - Improved appeals processes.
  - Prohibit rescissions of coverage based on a mistake on an application.



# Federal Temporary High Risk Pool has more comprehensive coverage than State programs

	<b>Temporary High Risk Pool (Preexisting Conditions Insurance Plan: PCIP)</b>	<b>Additional State High Risk Pool (HRP)</b>
Oversight/Funding	Federal	State: underwritten through assessments
Premiums	Premiums at standard rate in state	Premiums may run 105 to 250% of standard rate in state
Premium Variation	Age only	Age, pre-existing, gender
Benefits	Essential Health Benefits	May involve separate pharmacy rider
Limit on Enrollee Cost	PCIP pays at least 65% of beneficiary cost, not to exceed \$5950 individual in 2010	Limits vary- may have no annual limit or in excess of \$5950
Lifetime Cap	None	Yes
Eligibility: Citizenship	US Citizen, resident of state where they apply	State Residency requirements apply (6-12 months)
Eligibility: Conditions	Must be uninsured for 6 months	May apply to uninsured +/- insured with pre-existing exclusion May have waiting period

Slide developed by Christine Brown, National PKU Alliance

What does ACA mean in terms of genetics?

## Choice & Empowerment

- Advantage of “guaranteed issue”
- Portability
- More informed choice & uniform application processes
  - E.g., Provides standardized, easy-to-understand information on different plans available through the Exchanges



What does ACA mean in terms of genetics?

# Coverage and Benefits

- **Preventive services**
  - NOW, for new plans, no cost sharing on preventive services rated A or B by US Preventive Services Task Force (e.g. newborn screening).
  - In new Exchanges, coverage of prevention and basic health services, including maternity benefits.
- By 2014, DHHS to establish **essential standard benefits package**



What does ACA mean in terms of genetics?

## Consumer Protections

- Both GINA and ACA govern certain elements of health insurance and employment-based wellness programs
- ACA does not amend or reference GINA statutory requirements.
- The two laws interact, are complementary, and are not contradictory



# GINA and ACA Legal Intersection

- Congressional Research Office legal analysis found:
  - GINA privacy protections are much stronger, including prohibitions on obtaining/using certain information. GINA is civil rights legislation.
  - ACA guaranteed issue and renewal protections preclude denial based on health status (specifically including genetic information)
  - Under GINA plans/insurers may not adjust premiums or cost sharing based on genetic information; ACA applies only to premium rates
  - ACA protections (e.g., preexisting condition exclusions, guaranteed issue and renewability, premiums) apply to “*health insurance issuers*” (e.g., group and individual plans); GINA prohibits discrimination by all plans including “*self-insured group plans*”



# Equal Access to Genetic Tests Not Addressed

## **SACGHS: Recommendation 6: Ensure Equal Access to Clinically Useful Genetic Tests**

*“Given that genetic tests will be increasingly incorporated into medical care, the Secretary should ensure that those tests shown to have clinical utility are equitably available and accessible to patients.”*

- Such uniformity in coverage would ensure that all insured patients, regardless of geographic location or economic status, obtain access to clinically useful genetic tests.
- Our advocacy for equal access here is part of this Committee's long-standing concern about ensuring equity in the provision of genetically related tests and services. Earlier reports and recommendations have called attention to the importance of equitable access to genetic testing.



What does ACA mean in terms of genetics?

# Coverage and Benefits

- **Benefits must include:**
  - Ambulatory patient services
  - Emergency services
  - Hospitalization
  - Maternity and newborn care
  - Mental Health and substance use disorder services, including behavioral health treatments
  - Prescription drugs
  - Rehabilitative and habilitative services and devices
  - Laboratory services
  - Preventive and wellness services and chronic disease management
  - Pediatric services, including oral and vision care.
- **Core benefits defined; DHHS and board to develop details**





# The Essential Benefits Conundrum

“Beginning in 2014, the [ACA] will fine Americans who don't have health insurance that provides ‘**essential benefits.**’ The idea here is to eliminate Swiss cheese coverage and ensure that every American has comprehensive insurance....

As a result, medical special interest groups are already lobbying hard to try and get their products and procedures included in the “essential benefits” package, which is broadly outlined in the law, but which will be specifically defined by 2014.”

Kate Pickert. Time Magazine. 9/28/2010 <http://swampland.blogs.time.com/>



Kay Johnson. Presentation to the Secretary's Advisory Committee on Heritable Disorders in Newborns in Children. Annual Meeting of HRSA Genetics Collaboratives. January 28, 2011

# Genetic Services

- **Genetic services bundle**
  - Screening tests
  - Diagnostic and predictive tests in high-risk populations
  - Genetic counseling
  - PLUS treatment
- **Where do these fit in the broad categories of covered services?**
- **What does the U.S. Preventive Services Task Force say about genetic testing and counseling?**
  - B level recommendation supporting genetic counseling of women with family history of BRCA1 or BRCA2
  - A level recommendation for newborn screening for sickle cell disease and PKU
- **What should be financed by public health versus health insurance coverage?**



# Lessons Learned re: Benefits

**“Central Messages For The Public** - The ‘*What Matters Most*’ study and the Massachusetts Connector experience have demonstrated a much more resilient and able public than we might have anticipated... What we need to communicate to the public as we go forward are a few central messages:

- Not every service or treatment will be defined as essential, either in the benefit package or by the medical director;
- The real devilish details are described in the medical or clinical policies of the plan; and
- Even if a treatment is essential for some, it may not be essential for everyone.”

Source: Linda Bergthold. <http://healthaffairs.org/blog/2010/10/29/what-is-an-essential-benefit/>

Also see - <http://www.chcd.org/whatmattersmost/index.html>



Kay Johnson. Presentation to the Secretary's Advisory Committee on Heritable Disorders in Newborns in Children. Annual Meeting of HRSA Genetics Collaboratives. January 28, 2011

What does ACA mean in terms of genetics?

# Addressing Disparities

- Increase investment in primary care for medically underserved
  - Community health centers, NHSC, Medicaid primary care payments.
- Funding to increase workforce diversity
- Community health workers
  - Grants to States, public health departments, clinics, hospitals, FQHCs and other nonprofits.
- Investments in research about disparities



What does ACA mean in terms of genetics

# Integration with Public Health

- **Prevention and Public Health Fund**
  - Builds from \$500 million in FY 2010 to \$2 billion in FY2015 and thereafter
  - Will funds be committed to genetics and newborn screening?
  - Will child health, not just adult chronic conditions, be a priority?
- **National Prevention Strategy**
  - Core capacity for state and local health departments and others doing community prevention
  - Will genetics and newborn screening be a focus?
- **“Community Transformation” grants**
  - For state and local agencies and community-based organizations to implement, evaluate, and disseminate evidence-based community preventive health activities to reduce chronic disease, address health disparities, and develop stronger evidence-base.



What does ACA mean in terms of genetics?

# Quality & Efficiency

- National **quality** strategy and measures
- Patient-centered **medical home** pilots
- Patient-Centered Outcomes **Research Institute**
- CMS **Center for Innovation**
- Community-based **Collaborative Care Networks**
- **Community Health Teams** to support patient-centered medical (health) homes.



# Values and Health Care Reform

“There is a broad range of values that we want our health care system to embody and pursue – not just liberty but also justice and fairness, responsibility, medical progress, privacy, and physician integrity among others.”

Tom Murray, *New England Journal of Medicine*, January 28, 2010

